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Sharing Genetic Risk Information: Implications for Family Nurses Across the Lifespan

Alison Metcalfe PhD, BSc, RN, PG Certificate in Family Therapy, MBPS
Professor of Health Care Research
Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care
King's College London
57 Waterloo Road
London
England
SE1 8WA
Tel +44 207 848 3828
Email: Alison.Metcalfe@kcl.ac.uk
A.M.Metcalfe@SHU.ac.uk
Twitter: https://twitter.com/MetcalfeAlison

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Biographical Paragraph

Alison Metcalfe PhD, BSc, RN, PG Certificate in Family Therapy, MBPS, is a professor of Health Care Research at the Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care, King's College of London, England.

Alison's research is focused on the communication of genetic risk, in families, and between health professionals and patients. Having completed her nurse training and working as a nurse emergency care settings, Alison studied for a first degree in Biology and Psychology before studying for a PhD in biomolecular science. Throughout this period of study Alison worked part-time and on a volunteer basis in sexual health and family care.
Having worked in health care research management post-doctorally, she returned to a university role as a research fellow where she drew on all aspects of her education and experience to explore the impact of genetic testing technologies on patients and their families. Over the last 18 years this has culminated in a programme of work with a wide number of collaborators and PhD students to examine the implications of genetic screening and testing across the lifespan and the development of new interventions to facilitate family coping and adaptation to living with a genetic condition.
In addition to the research Alison teaches a wide range of health professionals nationally and internationally including undergraduate nurses, about family-centred care and continues to work in a family therapy clinic for one session per week to ensure her work remains relevant and grounded.

Recent publications include:

Mendes, A., Metcalfe, A., Paneque, M., Sousa, L., Clarke, A. J., & Sequeiros, J. (2017). Communication of information about genetic risks: Putting families at the center. Advance online publication. *Family Process.* doi: 10.1111/famp.12306

The Socio-Psychological Research in Genomics (SPRinG) Collaboration: Eisler, I., Ellison, M., Flinter, F., Grey, J., Hutchison, S., Jackson, C., Longworth, L.,…Ulph, F. (2016). Developing an intervention to facilitate family communication about inherited genetic conditions and training genetic counsellors in its delivery. *European Journal of Human Genetics, 24,* 794-802. doi:10.1038/ejhg.2015.215

Rowland, E., Plumridge, G., Considine, A. M., & Metcalfe, A. (2016). Preparing young people for future decision-making about cancer risk in families affected or at risk from hereditary breast cancer: A qualitative interview study. *European Journal of Oncology Nursing, 25*, 9-15. doi: 10.1016/j.ejon.2016.08.006

Abstract

Sharing genetic risk information in families can be very difficult. However, the consequences of poor communication can be detrimental to the psychological health and well-being of parents and children in the present and the long-term. Family nursing can play an important role in supporting family communication about genetic conditions. This role has several components: 1) improved assessment of families affected by or at risk from inherited genetic conditions; 2) facilitation of families discussions of genetic risk, especially between parents and children using an integrated model of family care to support parents and their children in the discussion of genetic risk information throughout the children's development including provision of assistance specifically for young people who wish to discuss the issues they face with informed nurses. And 3) there is a role for family nurses in educating other specialist nurses in taking a more family focused approach when they are caring for patients affected by genetic conditions. If the full benefits of genomic technologies are to be recognized and implemented, it is essential that the relational impact of the science be strengthened to enhance family relationships and support genetic risk information sharing.

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Address all correspondence to: Alison Metcalfe PhD, BSc, RN, PG Certificate in Family Therapy, MBPS, Professor of Health Care Research, Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care, King's College London, 57 Waterloo Road, London, England, SE1 8WA; Email: Alison.Metcalfe@kcl.ac.uk; A.M.Metcalfe@SHU.ac.uk

What I aim to establish in this article is the fundamental role family nursing can contribute to families' uptake of genomic technologies and the importance of specialist nurses working across all sectors of health services embracing a more family focused approach to care. Nurses have reported that genetics is about medicine and science (Metcalfe, Pumphrey, & Clifford, 2010) and has little relevance for them and their role in caring for the family. However, family nursing and genomics share the same population of interest in 'the family'; both areas use genograms (family nursing) or family pedigrees (genomics), which involves tracing family relationships.

On August 19, 2015, I had the privilege of giving a keynote presentation at the 12th International Family Nursing Conference in Denmark (https://internationalfamilynursing.org/2013/07/11/2015-conference/) sponsored by the International Family Nursing Association (https://internationalfamilynursing.org). I offered an overview of my program of research undertaken over the last 20 years that has focused on the communication of genetic risk information within families and the factors that impact on it and called for family nursing's greater involvement with families who are dealing with genetic issues. The work includes references that influenced my thinking and shows the context at the time of undertaking the research, although there has since been an exponential increase in research activity focusing on the socio-psychological impact of living with a genetic condition.

The purpose of this article is to increase the recognition of how the new era of genomic health impacts on families and to highlight the distinctive role that family nurses can play in order to provide much needed care that is required to facilitate families' coping and adaptation to genetic risk information and living with the condition. Opportunities

come with the genomic technologies, to work with families in new ways that empower them to drive and manage their health and well-being. There are opportunities provided by genetic information to know when there is an increased risk from disease, allowing the individuals to take steps to reduce the likelihood of disease. The opportunities are varied and may arise at different times in the life-cycle, for example there are reproductive choices for themselves or subsequent generations or prophylactic interventions with increased screening for early disease detection and health management through diet and medication and possibly surgery to prevent or delay the onset of disease. The benefits are easily recognizable and with continued advances in technology there is the prospect of targeted treatment and gene editing.

Juxtaposed with advancement however, there are also areas that jeopardize the successful use and uptake of the new genome technology. One major potential detrimental effect if the technology it is not integrated without due consideration, is for the effect on family relationships and the consequence for the family system– which is why family nursing is so salient. Genetic risk information can harm relationships, causing unnecessary tensions and friction unless people are supported in their use and integration of the information into their family and given opportunity to adapt to the risk and the genetic condition involved.

Genetic counsellors or medical doctors usually provide the genetic risk information often via genetic counselling but there is little long-term care and follow-up of the person receiving it (Mendes, Metcalfe, Paneque, Sousa, Clarke, & Sequeiros 2017). As genomic information is increasingly incorporated into standard care through routine screening of the genome, there is currently a void in where support is given to the individual, in their use

and sharing of genomic information within their family, once they have received their genome results.

Nurses can and do play a pivotal role in assisting families affected or at risk from a genetic condition to cope with and adapting to living with a genetic condition. As part of the care provision nurses should facilitate family communication about genetic risk, promoting cohesion, and relationship management. There is also the need particularly for family nurses to assist parents in providing the right level of information for their children to support family cohesion but to also ensure children and young people grow up to be resilient against the physical and psychological effects of the illness on them or their relatives. The integration of genomics into mainstream healthcare requires nurses to think about how they relate to families, and provide family-centred care, with family nurses having a pivotal role in care provision and sharing their skills and competencies to enable other nurses to take a more family-oriented approach wherever they provide care across the lifespan.

Background

An estimated 300 million individuals worldwide are affected by rare genetic conditions (Global Genes Website, 2017) compared with 15 million people globally affected by cancer (Cancer Research UK). These figures demonstrate that genetic conditions are not as rare as they are often considered and most nurses are likely to be caring for at least one family affected by a genetic condition.

Genetic conditions vary widely and may affect a person's health in a variety of ways including their life expectancy, quality of life, and their physical or psychological well-being. In Mendelian genetics, conditions are often described as autosomal dominant –

only one copy of the gene from a parent causes the condition or autosomal recessive where a copy of the affected gene is required from both parents for the disease to occur in a child and x-linked conditions, where the mother passes the affected gene to her son via the 'X' sex chromosome, and the 'Y' chromosome gene does not contain a copy of the unaffected gene to ameliorate the effects.

Mendelian genetic conditions have well recognized alterations in the genome code (gene variants) and the level of risk is relatively easily quantified. Children from a parent with an autosomal dominant condition have a 50% risk of developing the disease. In autosomal recessive conditions the risk is 25% and in X-linked conditions, boys have a 50% chance of developing the condition while girls have a 50% risk of being a gene carrier.

The introduction of rapid genome sequencing (genome screening) means that more disease causing 'genetic variants' are now being found (Genomics England, 2017). Some of the disease-causing variants are easily recognizable others are less well characterized. In some cases where the Mendelian rules of gene inheritance are less obvious, genome screening can detect variants that might be affected by other genes, which have a protective function and prevent the disease-causing gene from being expressed. While all this information can be explained to patients undergoing genome screening, there is little known about these gene variant interactions, and families may have an outcome which causes more questions than answers; leaving families to deal with the uncertainty caused by screening.

Where a person is diagnosed with a gene variant for causing disease, they are encouraged by health professionals to share the risk information with all those family members for whom there may also be a risk (D'Agincourt-Canning, 2001; McAllister,

Davies, Payne, Nicholls, Donnai, & MacLeod, 2007), allowing them to also take preventative measures. Most of my own and my colleagues' research has focused on what happens when families do or do not share genetic information and how does the communication about the condition affect how family members cope and adapt to living with risk and subsequently the genetic condition when it occurs. Between 30 to 50% of affected families in the USA were thought to struggle with coping and adapting to the psychological effects of living with a genetic condition (Biesecker & Erby, 2008; Gallo, Angst, Knafl, Hadley, & Smith, 2005).

Few studies have focused on the fundamental aspects of communicating and coping with an inherited genetic condition and the implications for the individual and their family long-term (Peterson, 2005; Rolland, 2006). The limited evidence that does exist is in small-scale studies, usually focuses on specific genetic conditions. These have shown that poor coping within the family is often related to poor communication and affects: children's psychological well being (Fanos, Davis, & Puck, 2001; Fanos & Puck., 2001; McConkie-Rosell & Spiridigliozzi, 2004); their reproductive choices as adults (Fanos, Davis, & Puck 2001; James, Holtzman, & Hadley, 2003); family cohesion and long-term caring (Sobel & Brookes Cowan 2000, 2003); and communication of risk information with extended family members (Kenen, Arden-Jones, & Eeles, 2004).

Family systems theory emphasizes the importance of open communication in families to promote coping and adaptation to difficult situations, not least in those affected by serious illness (Rolland & Williams, 2005). Therefore, if poor communication reduces individuals' ability to cope with the genetic condition, it is essential to understand what factors diminish or inhibit communication about genetic conditions and how nurses can

work with families across the lifespan to facilitate effective communication about the genetic condition to improve the outcomes for families coping with and adapting to living with the genetic disease and its risks.

Genetic Risk in Families with Children and Young People

Parents (includes anyone in a parental role) with children, who are still minors, often grapple with deciding when is the best time to explain about the genetic condition and its risk (Metcalfe, Coad, Plumridge, Gill & Farndon, 2008). The reasons for these difficulties are multiple but often associated with fears about worrying children (Gallo et al., 2005; Tercyak, Peshkin, Streisand & Lerman., 2001, Tercyak, Hughes, Main, Snyder, Lynch, Lynch, et al., (2001b); finding the right way to explain (Metcalfe, Coad, Plumridge, Gill, & Farndon, 2008; Metcalfe, Plumridge, Coad, Shanks, & Gill, 2011); feelings of guilt (Fanos & Puck, 2001); and fears about their own ability to psychologically cope with talking to their children and families (Miesfieldt, 2003; Miesfieldt, Cohn, Jones, Ropka, Weinstein, 2003; van Oostrom, Meijers-Heijboer, Duivenvoorden, JBröcker-Vriends, van Asperen, Sijmons, Seynaeve, van Gool, Klijn, Tibben, A. 2007; Metcalfe, Coad, Plumridge, Gill, & Farndon, 2008).

Family nurses can offer more tailored support to parents, to enable them to talk to their children about genetic risks and provide the information and support they require. Otherwise, the repercussions of poor communication and coping can reverberate through the generations because the strength of family relationships has the ability to enhance or stifle lives of parents and their children, through into adulthood.

Our research studies highlight the issues children, young people, and their parents' experience in talking about genetic risk information (Metcalfe, Coad, Plumridge, Gill, &

Farndon (2008); Metcalfe, Plumridge, Coad, Shanks, & Gill, 2011; Rowland & Metcalfe, 2013), and the unique issues that are observed in specific family groups (Plumridge, Metcalfe, Coad, & Gill, 2010, 2011, 2012). This included how children learn and cope with the information given, according to their age, inheritance patterns, disease type and its progression, which provide a platform and baseline knowledge for nurses to work with families to support parents' discussions of the genetic condition.

However, we also observed barriers that constrained families' communication about the genetic condition and associated risks, inhibiting discussion across the lifespan and which had potentially serious consequences for family relationships. An awareness of these issues by nurses caring for families at the different stages of the lifespan will provide opportunities to intervene and facilitate more open discussions within families. By focusing on a description of our research findings, we want to increase nurses' recognition of the issues and assist them in seeking family focused solutions.

Emotional Impact of the Genetic Condition

In pregnancy, men described the euphoria of learning that their partner was pregnant and that they were going to be fathers. As the pregnancy continued they described developing a bond with the fetus 'as their child' – making plans for its future as part of their family. Nevertheless, once their partner commenced antenatal genetic screening, many men described the 'emotional rollercoaster' that ensued (Dheensa, Metcalfe, & Williams, 2013; Williams, Dheensa, & Metcalfe, 2011). Men's ideas about the pregnancy were challenged causing ambivalence and confusion about their impending fatherhood and attachment to the unborn child (Dheensa, Williams, & Metcalfe, 2013). The long-term effects are not fully known but undoubtedly there are implications for the parent's relationship with each other

and for the father's bond with their newborn child, which if these issues are not addressed, might continue into the child's early years, where we know the input and emotional connectedness of fathers has the capacity to affect development (Bronte-Tinkew, Ryan, Carrano, & Moore, 2007; Cabrera, Fagan, & Farrie, 2008).

Following the birth of the child, where the results of postnatal genetic screening is given to parents, those parents whose children are diagnosed by a genetic condition describe how their relationship with their newborn is affected, reducing bonding and attachment, with parents' expressing fear and anxiety for their family's future (Chudleigh, Buckingham, Dignan, O'Driscoll, Johnson, Rees, Metcalfe, 2016). Nurses working with pregnant families and the newborn are therefore in a key role to recognize the impact and provide a more family centric approach to maternity care and genetic screening during the pregnancy and postnatally.

In our study (Metcalfe, Plumridge, Coad, Shanks, & Gill, 2011), our findings showed that at later stages of the family life cycle where children are growing and moving towards adolescence, the shock of the diagnosis of a genetic condition often inhibited communication between mothers and fathers, so much so that it could take between six months and two years before they could even talk to each other, let alone their children. Even when the genetic condition was known to be a risk in the family, there was still a sense of disbelief and even denial once a confirmed diagnosis was provided or symptoms became too apparent to ignore. Many parents experienced guilt as previously described but there were feelings of depression or anxiety reported, which had consequences for their own health and that of their engagement and attachment with their children (Cassidy & Shaver, 2008).

Many families experienced a large degree of isolation when they were affected by a genetic condition and because of a sense of stigma, they feared others finding out about the condition, or if their child has a serious learning or physical disability, which often prevented parents and their children from socialising with other families and friends. Or, as in many cases, some family members were not present having previously died from the genetic disease, which increased parents' feelings of isolation. The 'early' death of a parent's parent and / or their sibling or child had often left the surviving individual with unresolved grief reactions. These overwhelming feelings of grief had been present for many years and the parents concerned had received little help or support for it. This unresolved grief made explaining about the genetic risks and talking about family relationships, which this often necessitated, very difficult and upsetting. The embargo on discussion about the genetic condition affecting the family meant that children and young people had little opportunity to explore and correct their misperceptions about the genetic risks involved or update their knowledge to reflect their developmental stage.

In a research interview, the parent of a young person with Duchenne Muscular Dystrophy offered: "If you do talk about it, you think well it's a big subject. I'm not emotionally stable this week. I don't want to bring that up because I can't handle it, it's all about handling it yourself."

A parent who experienced a diagnosis of neurofibromatosis with two children reported:

> I just want to get on with my life really… I don't want to keep reminding myself all the time, I lost my Mum [died as a result of neurofibromatosis when the parent was a still a small child] and I lost my daughter, so there is a lot of emotional stuff there.

> I have dealt with some of it and I still am dealing with some of it… Sometimes I just, you know, I think well I don't really want to be there today.

Care Fatigue

For many parents, time for talking about genetic risk was limited by the day-to-day management of the genetic condition and caring for the family members affected. While many carried out the care willingly, the emotional and physical investment in providing care, attending numerous hospital appointments and co-ordinating health and social care professionals meant they often did not have energy psychologically to spend time discussing the genetic condition with their other children. The limited time parents had because of care commitments meant they wanted to spend 'quality time' with their children and so they avoided discussing genetic risk information.

Balancing commitments between affected and unaffected children, and self or partner was very difficult, and the majority of parents thought their unaffected children were often overlooked because they had insufficient time to spend with them. Parents and children had difficulties coping with the unpredictability of the genetic condition, in the short term with sudden deterioration in health, and the longer-term decline, which was often interspersed with acute events. Children and young people noted that care for the affected family member meant that life lacked spontaneity, they had to keep to rigid routines and often their parents were too tired to talk to them or spend time doing things they could all enjoy as a family. Many parents and children including those affected and unaffected by the genetic condition, resented it being such a strong focus in their lives and described trying not to think about it anymore than necessary.

A parent of a young person affected by Duchenne Muscular Dystrophy offered:

> I think our priority was to make sure that we were just, we were just existing, developing into being able to cope within the house. We didn't have leisure at the time, you know so that was out of the question… it's the siblings that are left all on their own, because I couldn't take her out anywhere, shopping, going on holiday.

A young adult whose siblings were affected by neurofibromatosis reported:

> I spent a lot more time with my dad, because of it, and my mum was, my mum was always there for my [affected] sister and my brother so in that respect I didn't have the whole, like, closeness with my mum, if that makes sense.

Parents often described the physical and emotional fatigue of caring. Carers were partners or children of the individual affected by the genetic condition. If they are the child of the affected person, they themselves may be affected or at risk from the disease, and having to cope with the likelihood of their own future care need. If they are the partner of the affected person, they have to consider the possibility of also caring for their child(ren), in addition to their partner. Therefore descriptions of anticipatory fear and grief about the disease and who or how it will affect the individual or their partner or child, were common in the families and yet none had access to health professionals who could provide support.

Parents providing care expressed an intense weariness at the effects of the condition on their family and the 'never ending need' for care. Some described a type of 'care fatigue'; where because of their own emotional need and well being they had to begin to choose which family members they would care for. By the time a third generation was requiring care, many parent carers felt unable to provide it, which could result in arguments

and family tensions leading to long-term relationship breakdown. This has significant consequences because the resulting rupture in family relationships meant some branches of the family lost contact with each other. The ruptures prevented communication of genetic risk information resulting in lost opportunities for future generations to make informed choices about genetic screening and testing.

With the parent of a young adult who tested positive for Huntington's Disease, the parent was already caring for her partner who was severely affected by the disease:

> I don't want to have to go from one caring role to, straight into another one…you know, I want some space knowing that I may have to look out for [daughter] when she … because I don't know when she'll start with it. … you know, I want some space …between the two.

Family Relationships

Family relationships obviously had a major impact on communication of genetic risk. In some families, parents disagreed about what children should or should not have discussed with them about the genetic risk involved. Children and young people were often very aware of these tensions but did not understand the reasons and as a result could become very stressed and upset. From interviews with parents and their children, it was apparent that genetic risk information was often given to all the family together, and whilst this helped with feelings of family cohesion, the younger members of the family had not always fully understood the discussions that took place. Particularly if younger children did not have insight into the implications or their older siblings asked questions they did not understand. Some parents were very good at recognising those differences and tried to follow up the initial discussion with each child separately, whereas others thought once

their children had been told and if they did not immediately raise questions, the child had no problems.

Siblings varied in the level of closeness they felt with each other. If the sibling had not received an explanation about their affected brother or sister's illness, they were more likely to describe distancing themselves and being resentful of their sibling. In some families, parents described how some siblings behaved very badly towards an affected brother or sister but in all cases the sibling had been told little about the illness. There was an assumption by the parents that because a child witnesses the disease everyday, they thought no explanation was necessary. Indeed, several parents suddenly recognized the omission during the interviews and were shocked at their own assumptions. Many of the parents said that they learned too slowly, the importance of more open communication about the genetic condition in cementing closer family relationships. They often saw dramatic positive changes in their children and young people's behaviour towards them and their siblings, once they understood what was happening.

A parent of child affected by Duchenne Muscular Dystrophy who has an unaffected sister reported:

> …my daughter was very angry. She wasn't aware of what was happening and all the attention was going on [affected brother]…her behavior was very irritable she blamed him for everything"…she helps me now, and helps [affected brother]… its a good family unit now; we all get on really well. So yeah, she does know everything now.

Many parents said they did not make long-term plans or encourage their children to, due to fears about what the future held in terms of the disease. Parents also often laid emphasis on siblings caring for and looking out for each other through into adulthood.

Children and young people affected by the genetic condition, were often reluctant to also talk too much about their plans beyond the immediate future but unaffected children often had significant plans that they did not always discuss with their families because they did not wish to be insensitive to their affected siblings.

Relationships with extended family were difficult across many families. Parents and children said this was sometimes related to communication of genetic risk, with parents' siblings not wanting their children to be aware of the genetic condition. The main route of communication about genetic risk to the extended family was usually through grandmothers and if she was not present, it did not usually take place unless an older sibling of the parents took on the role to make other family members aware of the risk. Interestingly, according to parents, grandparents approached about genetic testing were often reluctant and some refused when doctors were trying to establish the source of the affected gene to allow wider family testing. Again this caused tension in intergenerational relationships and restricted an important source of support for parents and grandchildren.

Sharing Information and Needing Support

Many parents said they actually struggled with explaining genetic risk information to their children because of their own limited knowledge. Parents had often received the information at diagnosis when they were too overwhelmed to process the information fully or it was a number of years since they received an explanation. All family members complained about the lack of resources to explain genetic risk. Information from clinicians and the Internet often focused on the disease and its treatment but not how to manage it.

A parent of a child affected by sickle cell disease said, "…well I find it a bit complicating myself [laughs] never mind a ten year old."

A parent of a child affected by cystic fibrosis reported:

> There's books for teenagers but there's not a book for the middle bit, or something that would help you explain when they get to that middle age which is probably about nine isn't it… I mean she knows that if she wants to go on the CF site she can ask and she can go and have a look on there but then there's not really a bit for her, it's just teenagers.

Children and young people often knew about the disease as far as the stage that was reached and evident in a family member. Parents however, rarely explained to them about disease progression, and only a small number of families had discussed mortality. Young people said they wanted their parents to talk to them about these issues but recognising that may be difficult; they suggested it should be with the support of health professionals for both parents and young people if required (Metcalfe, Plumridge, Coad, Shanks, & Gill, 2011).

The Pressures of Secrecy and Openness

Where families had previously tried to keep the genetic condition and / or its risks secret, parents and their children explained there had often been tensions, which they subsequently believed the secrecy had caused. Particularly there was often strife between siblings who blamed each other because they did not understand what was happening. The lack of opportunity to ask questions did not allow children and young people to correct their misperceptions or discuss their worries and concerns about what was happening. Some parents withheld the name of the condition from their children believing this would prevent them from finding out about it (via the Internet) and justified this by saying the

children never asked about it but not consciously realising children could not fully ask about something they could not name.

Many parents and children described the huge sense of relief they felt and in the parents case, they also observed in their children, once they knew and were able to discuss the genetic condition, even where the effects of the illness were severe or life-limiting. The father of a seven year old daughter with a mother affected by Huntington's Disease offered:

> ..it wasn't ohh boo hoo Mummy's poorly, it was a relief cause she understood, now she understood why Mummy was the way she was, and I just went God, that was a relief, why didn't I do it a year ago?...but she's quite funny, she'll say things like 'oh we know what the problem is don't we dad?' [laughs].

There were several other issues in relation to communication, which need consideration. A major one was that many parents set deadlines putting themselves under intense pressure, for when they would talk to their children for example: 'a few weeks before they go for genetic testing', 'when they enter a particular year x at school' or 'when they become sexually active'. All the parents described the dread and fear they felt as these deadlines loomed, making the parents lives even more emotionally difficult. Whereas families who had talked throughout their child's growing up, just took opportunities as they arose to give their child more information about the genetic condition, and would actively prompt their child on occasions. Conversely, the major downside of open communication meant that parents had to deal with children's fears about death and dying. However, all these parents said that despite the difficulty of discussing mortality with children particularly for a life limiting condition, they preferred to do that than maintain the secrecy,

which had been more destructive to their family's well-being. In some cases, parents had difficulty with young people's 'black' sense of humour about the genetic condition but it was not discouraged because this expression was viewed as a coping mechanism for their child.

Children and young people described feeling that they could not approach parents but also feared discussing the genetic condition and its risks outside of the family with many reluctant to discuss it with all but their closest friends, if at all. Parents and children often described a sense of 'taboo' that other people; extended family, friends or school and work colleagues were not comfortable discussing the condition, and some individuals reported active discrimination by employers for parents and in schools for children. This meant it was difficult to take time away from work to attend hospital appointments or meet health professionals, which limited time to learn and understand more about the genetic risks involved. As a way round these difficulties, many children and young people wanted to meet with other families who were in a similar situation to themselves.

For those genetic conditions where the disease can affect cognitive functioning or where learning difficulties are present, these resulted in particularly challenging situations. For example in Huntington's Disease, in some instances, parent's unwillingness to accept a diagnosis limited discussion of the condition, despite all the evidence of disease progression observed by confused children and young people. With the other parent worried about being disloyal to their partner's wishes and at the same time concerned about the impact on their children. This issue often worsened as communication diminished by the loss of physical ability for speech and facial expression, with children and young people experiencing difficulty in coping and feeling increasingly distant from their parent affected

by the disease. Whereas, possibly if the child had understood more about what was happening, it may have created a more empathetic relationship.

The Role of Family Nurses

What the accumulated studies have shown, over a period of many years is the benefits of more open family communication about the genetic condition and its risks have been established (Forrest Keenan, van Teijlingen, McKee, Miedzybrodzka, & Simpson, 2009; Mendes, Metcalfe, Paneque, Sousa, Clarke, & Sequeiros, 2017; Metcalfe, Coad, Plumridge, Gill, & Farndon, P 2008; Metcalfe, Plumridge, Coad, Shanks, & Gill, 2011). Better communication increases cohesion, improving long-term care and support within the family (Peterson, 2005; Rolland, 2006; Rolland & Williams, 2005). It also helps parents and children cope better with the genetic condition and its risks, and children appear to make informed reproductive choices as adults (Fanos & Puck, 2001). Family nurses and specialist nurses working with families affected by genetic conditions could greatly improve families' experience of living with a genetic condition if a more family-centric model of care is applied. Nurses taking a family centred approach can support parents in adjusting to the genetic condition and its risks, and facilitate helping their children to learn and cope too.

Family nurses and specialist nurses caring for family members at different stages from across the life cycle can use assessment to interrogate the specific issues faced by families affected by a specific genetic condition and their concerns about more open communication about it and the risks. The insight provided will allow more targeted support to families to facilitate their coping and adaptation to living with the genetic condition through improved family communication from the point of screening and

diagnosis through to end of life care (Lillie, Clifford, & Metcalfe, 2011; Rowland, Plumridge, Considine, & Metcalfe, 2016).

At the point of diagnosis, parents were given information when they were emotionally fraught and anxious, and often with minimal, if any follow up across the medium to long-term. Many individuals are often also dealing with challenging situations from their own upbringing as a result of the genetic condition, including death of their parent whilst they were still a child, and the lack of openness about the genetic condition in their own childhood. Nurses can provide information and develop parents' skills and confidence to deal with children's questions and emotions about the genetic condition from childhood to adolescence, which will allow them to reach adulthood confident in their knowledge and coping too. Giving families this confidence will also empower them, reducing feelings of stigma and lessening their isolation.

Families affected by inherited genetic conditions may face circumstances where there is the prospect of caring for two or more generations of family members, knowing that they and their children are at risk from or affected by the same disease, which carers supporting individuals with other chronic conditions are unlikely to face. Caring for a person with an inherited genetic condition can lead to increased stress (Nereo, Fee & Hinton., 2003) and a poorer quality of life for the carer (Aubeeluck and Buchanan, 2007), leading to anxiety and depression, which is often described by carers in families affected by chronic conditions (Department of Health, 2008) but these effects are often compounded in families affected by genetic conditions (Waldboth, Patch, Mahrer-Imhof, & Metcalfe, 2016). With poor psychological health in parents known to impact on their attachment and relationships with family members, it is essential family nurses recognize these stressors

early on. Many parents described the limited time and emotional energy they had for talking about the genetic condition and its risks with their children. In part also due to the unreliability and lack of co-ordinated service delivery and health or social care support, which they described, as exhausting as they tried to negotiate the gamut of service provision. Greater support in care provision and more co-ordinated service delivery should therefore facilitate improved family communication and family nurses can play a central role in supporting carers and helping them manage the health and social care support effectively.

Independently of each other, early death or multiple deaths in a family affect people's grief reactions (Kissane, Bloch, McKenzie, McDowall, & Nitzan, 1998; Tomarken, Holland, Schachter, Vanderwerker, Zuckerman, Nelson, Prigerson, 2008). For those affected by life threatening inherited genetic conditions both early death and multiple deaths are likely to be a feature of the family's experiences, within the same generation and subsequent ones. This probably explains why many parents described unresolved grief reactions particularly about parental loss, which made discussion of family history as part of explanations about genetic risk with their children too painful and too emotive. However, inhibition of discussions because of bereavement impedes young people's reproductive decision-making, and affects adults' choices about genetic counselling (McAllister, Davies, Payne, Nicholls, Donnai, & MacLeod, 2007). This underlines the need for end of life care provision for families affected by genetic conditions that recognizes the specific difficulties faced in families affected, which many nurses in end of life care are often unaware (Metcalfe, Pumphrey, & Clifford, 2008; Metcalfe, Pumphrey, & Clifford, 2009; Metcalfe, Pumphrey, & Clifford, 2010).

Conclusion

Through the presentation I highlighted the many issues families face when they are affected by or at risk from an inherited genetic condition and the need for nurses' increased awareness of the necessity for family focused care to manage the situations that arise. The management of genetic conditions affects not only the present generation but has life-long repercussions that affect future generations. Empowering the present generation will greatly enhance future generations' experience and management of the genetic condition, and family nurses can play a significant role.

However, family nurses require suitable education and skills to assist them in facilitating family communication about genetic conditions, and we need educational programmes that recognize the relational impact of genomics, not just the science. Family focused care including assessment and intervention and an understanding of genomics needs to be integrated into undergraduate and postgraduate curricula in nursing.

Genomics and genetic science is having a socio-psychological effect on individuals and their families. Patients and families need time to assimilate and cope with the genetic information and many need support from nurses to make sense of and use the genetic risk information effectively. While consideration is required about how that risk information is used and not imposed on families. My colleagues and I within the Socio-Psychologial Research in Genomics (SPRinG) Collaboration have been developing interventions to facilitate improvements in family communication about genetic conditions (Eisler et al., 2016, 2017) and we are keen to collaborate with family nurses and nurses working in specialist fields to take this forward.

Developments in genomics have exposed the flaws in service provision, where care of ‘the family’ is often lacking. Only a more family-centric approach through better education of family nurses who can work with families will see genomic information used to its fullest and most beneficial effect.

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